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**Miscarriage, Stillbirth and Newborn Death**  
**1st Edition, May 2018**

Sands is a not-for-profit organisation supporting bereaved families across Australia whose baby has died through miscarriage, stillbirth or newborn death.

Visit: [www.sands.org.au](http://www.sands.org.au) for more information about Sands' support services.

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# Background and Purpose

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Each year in Australia, there are approximately 106,000 miscarriages, stillbirths and newborn deaths. This includes 103,000 miscarriages (<20 weeks' gestation), 1700 stillbirths and 700 newborn deaths (abs.gov.au, 2017, Herbert, Lucke & Dobson, 2009). This number is catastrophic, meaning that miscarriage, stillbirth or newborn death will occur to 1 in 3 Australian women in their lifetime.

The Sands Australian Principles of Bereavement Care have been developed to identify key actions and behaviours that can ensure that all bereaved families receive high quality care and support following the death of a baby.

The psychosocial and emotional impact on mothers, families and society in general is substantial, yet the care received by parents in Australia is highly variable. Review of our survey results show bereaved parents' needs are frequently unmet. Parents face many critical decisions following the death of a baby and more support and guidance is needed so that healthcare professionals have the information they need to deliver high quality care to all bereaved families (Sands Bereaved Parents Survey, 2016).

Research carried out by the Stillbirth Foundation (2015) tells us that grieving parents want maternal staff to demonstrate sensitivity and empathy, validate their emotions, provide clear information, and be aware that the timing of information given may be distressing. Parents also want support and guidance when making decisions about seeing and holding their baby. Sensitivity, respect, collaboration, and access to information is essential throughout the experience of miscarriage, stillbirth or newborn death (Sands Bereaved Parents Survey, 2016).

Research shows that while there have been many improvements over the last three decades, there are still many parents and families who do not receive quality care and support following the death of their baby. Sands' data collected identified a number of key issues in the bereavement care experienced by many parents who went through early pregnancy loss, medically advised termination, stillbirth or newborn death.

## Key findings

- 60% of bereaved parents surveyed felt cared for and supported by hospital staff. To some extent this depended on whether their experience was recent (generally more positive but not always) or more than 15 years ago when the culture of bereavement care for baby loss was lacking.
- 51% of parents felt ill-informed about the grief they were going to experience, 29% felt informed and 13% were unsure.
- Just over half of respondents (54%) were provided with supportive information or literature to take home.
- There is inconsistency in the services delivered and knowledge of appropriate bereavement care.
- There is a lack of continuing support for bereaved parents after they leave hospital.
- Many parents are not being referred to external peer-to-peer support services (Sands or similar).
- Health professionals lack adequate training in bereavement care.



# Working in Partnership

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Sands has worked in partnership with The Centre of Research Excellence in Stillbirth (The Stillbirth CRE) to develop these Principles. Whilst Sands has an array of knowledge and experience in the field of bereavement support and has a very strong understanding of parents' needs, the high-quality research provided by the Stillbirth CRE is a vital contribution and ensures that the Principles are underpinned by a strong evidence base.

### About Sands

In 1979 Sands was founded as a place for parents who have experienced the death of a baby to meet up and discuss their shared grief. Whilst the organisation has expanded and grown since that time, it is still this yearning for belonging that underpins everything we do. Sands is the leading provider of bereavement support services in Australia, providing direct emotional support to over 5,000 bereaved families each year. Our model of peer-to-peer support places Sands in a strong and unique position to provide hope and understanding to bereaved parents and their families across Australia.

Sands' support services include a national support line, men's support line, email support service and live chat, the first online live support one-on-one chat for bereaved parents. Face-to-face support groups are also delivered across many states. Sands distributes key information via digital and print brochures, available through health services, Sands offices and our website. Sands trained volunteers and staff deliver thousands of hours of training for health professionals both online and face-to-face to help develop their bereavement care skills.

### About the Stillbirth CRE

The Stillbirth CRE was established to reduce the rate of stillbirth and improve care for parents and families whose baby is stillborn. The Stillbirth CRE is an Australia-wide initiative, hosted at the Mater Research Institute, within The University of Queensland Faculty of Medicine and is funded by the National Health and Medical Research Council of Australia.

The Stillbirth CRE recognises that stillbirth has enormous economic and psychosocial impacts; that there has been virtually no reduction in rates of stillbirth for over 20 years; that large equity gaps exist; and that families whose child is stillborn often receive suboptimal care (Stillbirth CRE, 2017). The Stillbirth CRE works in close partnership with the Perinatal Society of Australia and New Zealand, a multidisciplinary society dedicated to improving the health and long term outcomes for mothers and their babies. The Stillbirth and Neonatal Death sub-committee of PSANZ (PSANZ SANDA) played a major role in the development of the Stillbirth CRE and the Stillbirth CRE is now the Coordinating Centre for PSANZ SANDA.

The Stillbirth CRE program is based on The Lancet's 2016 Ending Preventable Stillbirths Series Call to Action and the specific priorities identified for Australia (Flenady et al., 2016). As the same interventions that may reduce stillbirth can also reduce adverse maternal and newborn outcomes, by implementing these interventions, the Stillbirth CRE aims to reduce a range of adverse pregnancy outcomes, with stillbirth its core focus. The Stillbirth CRE is a collaboration of parents, parent advocates, clinicians, researchers, professional colleges and policy makers, to generate new knowledge that translates into practice change and improved outcomes.



## Continuing the Partnership

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Sands and The Stillbirth CRE will continue to work together to develop best practice bereavement care and research in the area of pregnancy loss. Sands has recently contributed to the update and expansion of the current PSANZ Bereavement Care Guidelines.

## Endorsements

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Sands would like to thank the following organisations for their endorsement of the Principles.

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# Principles of Bereavement Care

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## **Principle A: Individualised Bereavement Care**

Bereavement care should be individualised to recognise bereaved parents' personal, cultural or religious needs. To deliver tailored bereavement care, time needs to be spent with bereaved parents to gain an understanding of their wishes.

## **Principle B: Good Communication**

Communication with bereaved parents should be clear and honest. Consideration should be given to specific language to ensure it is empathic and sensitive. The term 'your baby (or babies)' should be used in all conversations (terms such as fetus, embryo, spontaneous abortion should be avoided). Trained interpreters and signers should be available for parents who need them.

## **Principle C: Shared Decision Making**

Parents should be provided with full information into any important decisions to be made regarding themselves or their baby (babies). Parents should be given adequate time and information to consider all options available to them.

## **Principle D: Recognition of Parenthood**

Recognition of parenthood and the role of memory making is vitally important and is thought to assist with the actualisation of grief and the slow transition of the parents' relationship with their baby from one of presence to one of memory. One of the greatest regrets that bereaved parents report to Sands is the lack of memories of their baby.

## **Principle E: Acknowledging a Partner's and Family's Grief**

Recognition that a partner's and family's grief can be as profound as that of the mother and that their need for support should be considered and met. It should be clearly communicated to both the mother and her partner that support services are available to them individually and that it is helpful to talk to someone if they require support.

## **Principle F: Acknowledging Grief is Individual**

Recognition of the grief journey and that all bereaved parents will handle and react differently to grief. The intensity and duration of grief for each bereaved parent will be different. Recognition that it is common that even within the same family each parent may react and handle grief differently. Health professionals should make parents aware that different grief responses are normal and that there is no perfect way to grieve.

## **Principle G: Awareness of Burials, Cremations and Funerals**

All babies, no matter the gestation, should be treated with respect at all times. Options for burial, cremation, taking baby home, home funerals and conventional funerals should be discussed before baby is born, if possible, to give as much time to organise, consider and for all options to remain open. Health professionals should be aware of burial, cremation and funeral options available in their local area.

## **Principle H: Ongoing Emotional and Practical Support**

Bereaved parents should be provided with information and referrals to both professional support and peer-to-peer support services such as Sands. The concept of seeking support (professional or peer) should be normalised for the bereaved parents and encouraged. Bereaved parents who have accessed peer support services such as Sands have reported that they feel their grief was heard, understood, and validated and have greater prospects of hope for the future.

## **Principle I: Health Professionals Trained in Bereavement Care**

All health professionals who interact with bereaved parents should be aware of the Sands Australian Principles and should aim to attend professional development opportunities on bereavement care to ensure that the goal of consistent bereavement care across Australia is achieved.

## **Principle J: Health professionals with Access to Self Care**

It is ok to not be ok after the death of a baby. All staff who care for bereaved parents before, during and after the death of a baby will be affected emotionally. Health professionals are in the 'helping' profession and when they cannot help this can bring up difficult emotions. Staff should have good access to information about effective self care.





## Principle B:

# Good Communication

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Communication with bereaved parents should be clear and honest. Consideration should be given to specific language to ensure it is empathic and sensitive. The term 'your baby (or babies)' should be used in all conversations (terms such as fetus, embryo, spontaneous abortion should be avoided). Trained interpreters and signers should be available for parents who need them.

### Rationale

The death of a baby is a tragic experience that is unique for every bereaved parent. No one can be prepared for the devastating grief that follows. A family's dreams for the future with their child are lost and their heartbreak is immeasurable. The death of a baby or child is known to evoke one of the strongest grief responses in one's life.

Grief is incredibly complex, individual, and has real effects in terms of losses of normal cognitive functioning in some circumstances (Hall et al., 2014). It is therefore important that all interactions with bereaved parents have in mind the need for clear and consistent communication. Good communication increases the likelihood that parents feel informed, heard and respected and that their wishes for memory making and other aspects of care for their baby are delivered in the individual way they require.

Bereaved parents have reported to Sands, even many decades after the death of their baby, that good communication is vitally important and can have a significant impact on the choices they make. Bereaved parents have reported that they can still hear certain 'phrases' in their head many years later and that this can affect a positive memory of their baby. An example of this is a bereaved parent recalling the moment that their baby was referred to as a 'fetus that is incompatible with life'.

Health professionals should understand the long lasting impact their words and actions may have on bereaved parents and communicate with them in a sensitive and responsive way.

### When health professionals communicate well with bereaved parents they:

- Avoid clinical terms such as fetus, embryo, and spontaneous abortion.
- Ensure that language or disability is not a barrier to memory making and other important decisions by ensuring trained interpreters or signers are available for key discussions.
- Ask parents for permission to call their baby by name, if the baby has been named, and ensure all staff continue to refer to the baby in this respectful way.
- Use intuitive questioning to really understand their position.
- Actively listen to parents to ensure their needs are being appropriately met (they don't just tick off a check box).
- Pay particular attention to the environment in which they deliver bad news or have difficult conversations, choosing private areas over hallways or common spaces, for example.

## Principle C:

# Shared Decision Making

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Parents should be provided with full information into any important decisions to be made regarding themselves or their baby (babies). Parents should be given adequate time and information to consider all options available to them.

### Rationale

Evidence suggests that shared decision making provides numerous benefits for parents, health professionals, health services and the healthcare system (Oshima Lee & Emanuel, 2013). Parent led decision making is found to reduce healthcare costs as well as importantly providing increased knowledge to parents, resulting in less anxiety about care processes and greater alignment of care practices with parents' values (Oshima Lee & Emanuel, 2013).

Bereaved parents have reported to Sands that when decisions about their baby's care have been taken out of their hands they feel like their parenthood is not being acknowledged (Sands, 2016). Conversely, when parents are encouraged to be a part of those shared decisions it provides an important opportunity for them to parent their baby (Sands, 2016). Given the chance, most parents report that they want to be involved in as many decisions about the care of their baby as possible.

It should be noted, however, that grief may mean it is difficult for parents to lead the decision making process and that health professionals may need to support parents when they feel confused or under pressure.

### Health professionals can involve parents in decision making by:

- Using decision-aids such as Sands' range of information booklets to inform and empower parents to make informed decisions.
- Offering choices around what could happen next. For example, will baby leave hospital to go to the funeral home or will baby stay at the parents' home until the funeral?
- Providing opportunities for them to parent their baby. For example, by taking their baby outside into the natural light or for a walk in a pram.
- Suggesting they name their baby.
- Involving parents in decisions around memory making and the taking of photographs.
- Involving parents in decisions around autopsy consent.
- With the parents' consent, including others, such as family members or spiritual leaders, who may help them in their decision making.

**When parents are encouraged to be a part of those shared decisions it provides an important opportunity for them to parent their baby.**

## **Rationale**

Memory making, as well as language, is thought to assist with the recognition of parenthood for bereaved parents. Within the many stories bereaved parents share with Sands each year is the recurring theme of regret – regret at not spending enough time with or making enough memories of their baby.

Information about memory making and care packages should therefore be given to bereaved parents early enough for them to take up those opportunities. All individual wishes, needs and cultures/religions

# Acknowledging a Partner's and Family's Grief

Recognition that a partner's and family's grief can be as profound as that



## Principle G:

# Awareness of Burials, Cremations and Funerals

All babies, no matter the gestation, should be treated with respect at all times.

Options for burial, cremation, taking baby home, home funerals and conventional funerals should be discussed before baby is born if possible, to give as much time to organise, consider and for all options to remain open. Health professionals should be aware of burial, cremation and funeral options available in their local area.

### Rationale

Coming home from the hospital without your baby is a devastating experience for most parents. Mothers, in particular, often describe this as the hardest part of their experience. Bereaved parents say that having to separate themselves from their baby and walk away from the hospital is extremely difficult. Many say these physical actions went against a strong motherly instinct to be with their child and protect them.

No matter the gestation of the baby, parents should be given options for burial, cremation or to take their baby home.

Organising a funeral or similar service can be a very frightening and confusing experience for parents. Normalising this experience and providing resources that have been helpful for other families is something health professionals can do to assist bereaved parents during this process, including providing information about what services are available in the local area.

A funeral or memorial service is one of the only things bereaved parents get to do for their baby. Therefore, it is important that discussions are had in a timely manner to allow bereaved parents a full range of options for their baby. Bereaved parents, especially if they are unexpectedly a large distance from home, may need extra time to discuss their options for burial or cremation and make arrangements. Health services should encourage parents to take their time to make these significant decisions and be accommodating of this extra time.

Bereaved parents should also know that there are times, when appropriate, that they can take their baby home for a period of time and this should be normalised. It should also be noted that parents should be made to feel that it is ok if they also decide not to do this.

### To inform bereaved parents of their options for burials, cremations and funerals health professionals should:

- Give parents options to take baby home.
- Let the parents know that they have options beyond the traditional.
- Be aware that some babies under 20 weeks can be taken home for burial (check state information).
- Have a very good understanding of services available in their area.
- Prepare bereaved parents for having the first conversation with a funeral director (if using). Funeral directors have a specific set list of questions that they have to ask, often by law (such as parents' occupation, mother's maiden name etc.) which may be difficult for parents to respond to. Funeral directors have reported to Sands that it is helpful from their perspective if the health professional prepares the bereaved parent for this initial phone call.

No matter the gestation of the baby, parents should be given options for burial, cremation or to take their baby home.

## Principle H:

# Ongoing Emotional and Practical Support

Bereaved parents should be provided with information and referrals to both professional support and peer-to-peer support services such as Sands. The concept of seeking support (professional or peer) should be normalised for the bereaved parents and encouraged. Bereaved parents who have accessed peer support services such as Sands have reported that they feel their grief was heard, understood, and validated and have greater prospects of hope for the future.

### Rationale

Sands research indicates that at least half of all bereaved parents are not given information at the hospital about continuing support services (Sands, 2016). Ongoing support is an essential part of bereavement care and should be made available to all who want it, including during subsequent pregnancies.

All parents should receive information for both professional and peer-to-peer support services, such as Sands, before leaving the hospital. Details of the support services offered should be discussed with parents as well as detailed in handover documents to the bereaved parents' primary care GP or other allied health services.

Peer-to-peer support has been found to be especially beneficial in the normalisation of grief processes and in transitioning from the hospital to the home environment (Legere, Nemeč & Swarbrick, 2013). Grief is lifelong and ensuring that evidence based peer-to-peer support is offered ensures that bereaved parents are supported even throughout subsequent pregnancies (if experienced) (Koopmans, Wilson, Cacciatore & Flenady, 2013). Bereaved parents continually report that the support received through Sands' peer-to-peer support model validates their grief and provides a place where they feel safe, heard and understood.

Health professionals should discuss the range of peer-to-peer support services available to parents, such as Sands' national phone support line, online live chat support, online resources, brochures and face-to-face support groups.

At this time, it is also helpful if other family members are directed to information about how best to support the bereaved parents. Sands' support services are also available for friends. Brochures specifically for family, friends and grandparents about how to be an effective support are available for free download at [www.sands.org.au](http://www.sands.org.au).

### To ensure they provide parents with options for ongoing emotional and practical support health professionals should:

- Talk through the different options of continuing support (professional and peer support).
- Provide a Sands Bereavement Care Package, if hospital supplies and space permits.
- Provide Sands information brochures.
- Discuss the Sands live chat support service available online.
- Ensure that all bereaved parents receive a follow up call and/or visit from a maternal health or allied health professional in addition to the regular referral to their general practitioner.
- Acknowledge that while continuity of care can be challenging, it can be achieved through effective communication.





# Health Professionals with Access to Self Care

It is ok to not be ok after the death of a baby. All staff who care for bereaved parents before, during and after the death of a baby will be affected emotionally. Health professionals are in the 'helping' profession and when they cannot help this can bring up difficult emotions. Staff should have good access to support and practice self care.

When birth and death are fused together there is a confusion of thoughts and feelings, as well as a totally bewildering sense of unreality' (Kenworthy & Kirkham, 2011). If you are emotionally affected by the death of a baby and need support you are able to call the Sands national support line as well as other support lines.

## **Rationale**

Many health professionals suffer from vicarious traumatisation, due to exposure to workplace stressors (Saakvitne et al., 2000). Vicarious traumatisation, more

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